

**TESTIMONY BEFORE THE WHITE HOUSE SUBCOMMITTEE ON THE
DELIVERY OF RELIABLE AND USEFUL INFORMATION ON
COMPLEMENTARY AND ALTERNATIVE MEDICINE**

Good afternoon. My name is Diane Cole, and I am an education coordinator at the University of Virginia Cancer Center. I address you on behalf of health care providers and educators who are mandated to educate patients and their families at cancer centers across the country.

What we know is that 50% or more of all cancer patients are using some form of complementary or alternative therapy; we are trying to address the quality of that information, for the protection of the patient. Our patients are very vulnerable to being taken advantage of by companies and products whose bottom line is profit instead of cure or quality of life. Many of them trust their health professionals to provide excellent medical care, but they want to do more for themselves that help them feel in control.

These patients are making decisions about and are spending thousands of dollars on some therapies and products that have very inconsistent data to support their benefit. When they search the web, there is no standard on which to judge the credibility of the websites. Many patients will not tell their physicians what CAM therapies they are using, and many physicians do not feel comfortable advising their patients about what CAM therapies to use, if any.

Members of our network hear patients express their frustration and confusion about what they should be doing in terms of CAM every day. In response to this, we have developed a Guide to CAM Resources which is not exhaustive, but it gives patients a start. This Guide is provided in your packet of information.

Our network offers the following observations for your consideration, based on our experience with this patient population:

- Students preparing to be health care professionals, as well as those already in the field, should be educated on complementary and alternative medicine practices and interventions. A better understanding of CAM services by all health care professionals is the best way to eliminate barriers and make CAM services more accessible.
- An oversight department in Health and Human Resources must be at the forefront of consumer safety issues, responsible for the labeling of herbal “natural” products and supplements. Consumers should be able to read a label and make good decisions about possible side effects and/or food/drug interactions.
- Medicare and third party reimbursement should be available to include modalities such as massage, acupuncture, and visits with other certified practitioners. Research

in this area could prove that there is a real potential for tremendous cost savings to the burden of the present health care delivery system.

- Lastly, more research is needed in complementary and alternative medicine modalities. Research should encompass case studies and clinical trials that include the study of the placebo effect.

Thank you for the time dedicated to this important topic of Complementary and Alternative Medicine that now occupies a prominent position in the delivery of health care services to our cancer patients.

Summary
White House Commission on Complementary and Alternative Therapy
May 16, 2001, Public Testimony
Presentation by Diane Cole, M.P.H.

Who we are:

A group of patient educators at NCI Designated Cancer Centers throughout the country. Included in our group are MD's, social workers, psychologists, chaplains, nurses, and health educators.

Who we serve:

Cancer patients and members of our communities

Within our network, we serve the needs of cancer patients (pediatrics and adults) throughout the spectrum of care – this includes diagnosis, treatment, rehabilitation, and end-of-life care. Many of us also serve our communities at large, providing education and awareness to people regarding health, lifestyle, and the early diagnosis of cancer.

Description of the Need:

- Fifty percent or more of all cancer patients are using some form of complementary or alternative therapy.
- Many patients trust their physicians to provide excellent medical care, but they want to do more for themselves that help them feel in control.
- Patients are making decisions about and are spending thousands of dollars on some therapies and products that have very inconsistent data to support their benefit.
- When patients search the web, there is no standard on which to judge the credibility of the websites.
- Many patients will not tell their physicians what CAM therapies they are using, and many physicians do not feel comfortable advising their patients about what CAM therapies to use, if any.
- The cancer patient population is very vulnerable to being taken advantage of by companies and products whose bottom line is profit instead of cure or quality of life.
- Education needs to be provided to let them know the importance of rigorous evaluation, and clinical trials are essential to knowing a therapy's risk and benefit. Patients are frustrated with the time clinical trials take to prove benefit to the cancer patient.

What We Have Done:

- Provided assistance in the past 2 years in developing parts of Dr. Jim Gordon's conference "Comprehensive Cancer Care: Integrating Complementary and Integrative Medicine."
- Developed a Guide to CAM Resources that we distribute throughout our network (attached).
- One member has contributed to a comprehensive guide to complementary and alternative therapies that can be found at <http://www.canctr.mc.duke.edu/pated/CAM.asp>
- Compiled a list of CAM fact sheets that have been written by and are provided at institutions across the country.
- We are currently in the process of developing FAQ sheets on CAM therapy.

Our recommendations to the White House Commission on Complementary and Alternative Therapy:

- Better education for all students preparing to be health professionals. This includes incentives for medical schools and nursing schools to include CAM information in their curriculum.
- More opportunities in continuing education for health professionals currently in the field. Continue the annual CAM conference and provide other affordable opportunities for education.
- Establish a department that regulates the labeling of herbal "natural" products and supplements. This department should also provide education to the public regarding reading labels, side effects, and food and/or drug interactions. Labeling should accommodate those of low literacy.
- Pass legislation that can expand third party reimbursement to cover more CAM therapies with certified practitioners (massage, acupuncture, meditation, etc.)
- Regulate the gathering of natural products from our world's rainforests.
- Increase funding for research that includes clinical trials on all aspects of CAM, including the placebo effect, pain management, and end-of-life care. Provide avenues where this research is then communicated to all health professionals and the public.
- Create a "seal" (like the Better Business Bureau has done) to indicate a standard of information provided on websites. This could be one indication for the consumer of reliable information.
- Provide better information to the consumer on how to evaluate studies, practitioners, and new products.
- Encourage collaboration among health organizations, such as what is being done within the patient education network, to work together not only on research but also on public education. Encourage collaboration especially between the mainstream/allopathic world and the CAM world.